NEW ZEALAND COLLEGE OF MIDWIVES (INC)

20th June 2018

New Zealand Consensus Statement on the Care of Mother and Baby(ies) at Periviable Gestations

FEEDBACK FROM New Zealand College of Midwives
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The New Zealand College of Midwives is the professional organisation for midwifery. Members are employed and self-employed and collectively represent 90% of the practising midwives in this country. There are around 2,900 midwives who hold an Annual Practising Certificate (APC). These midwives provide maternity care to, on average, 60,000 women and babies each year. New Zealand has a unique and efficient maternity service model which centres care around the needs of the woman and her baby.

Midwives undertake a four year equivalent undergraduate degree to become registered. The undergraduate curriculum meets all international regulatory and education standards. Midwives are authorised prescribers in relation to their Scope of Practice as determined by the Midwifery Council.

Midwives provide an accessible and primary health care service for women in the community within a continuity of carer model as Lead Maternity Carers. Midwives can also choose to work within secondary and tertiary maternity facilities, providing essential care to women with complex maternity needs.

The College offers information, education and advice to women, midwives, district health boards, health and social service agencies and the Ministry of Health regarding midwifery and maternity issues. Midwives interface with a multitude of other health professionals and agencies to support women to achieve the optimum outcome for their pregnancies, health and wellbeing.

NEW ZEALAND COLLEGE OF MIDWIVES (INC)

5th June 2018

New Zealand Consensus Statement on the Care of Mother and Baby(ies) at Periviable Gestations

Introduction

Thank you for the opportunity to provide feedback on the draft consensus statement regarding the care of Mother and Baby presenting at periviable gestations. It is acknowledged that while babies are not often born at these very early gestations (23^{+0} to 24^{+6} weeks); when they are it is a very difficult experience for parents and whanau, always with significant short to medium term challenges and sometimes with considerable long term consequences. Decision making both for families and for clinicians is complex but it is acknowledged that parents and whanau have the right to make decisions about active or palliative care for their babies born at these gestations.

Access to tertiary level maternity and neonatal care services varies geographically. Women and whanau are often required to make decisions regarding planned care for their baby outside of the tertiary centres; particularly in regard to decisions for palliative care vs active intervention. These decisions determine planning for care including transfer to a tertiary centre and the commencement of treatment to best prepare baby for birth at these extremely premature gestations. To ensure equity of service and equity of access to service, consistent messaging and counselling services are required throughout the country. Guidelines to assist clinical teams and in particular parents and whanau to traverse the very complex decision-making process are necessary to support this.

The New Zealand College of Midwives is aware that babies will be born in all contexts including rural primary units as women urgently access the nearest possible care. It is therefore important that guidelines provide appropriate guidance for midwives practicing in those more remote areas along with the women and whanau they support.

Feedback on Recommendations of Care

1. *All parents faced with the difficult situation of preterm birth at a gestation between 23 to 24^{+6} weeks should be offered multidisciplinary and family/whānau-centred counselling and support in a consistent and informed way from a team of senior care providers.*

Agreed; in many contexts throughout the country urgent decisions need to be made when immediate access to paediatric and obstetric specialists is not possible and some discussion needs to occur prior to transfer. It is important that midwives are included in the team of senior care providers and can support both remote discussions with paediatric teams and hold initial discussions with families and whanau and have sufficient resource to support those discussions.

2. *At 23 to 24+6 weeks options to be considered should include active intervention or supported comfort/palliative care. Considering active intervention from 22^{+5} weeks gestation allows time for preparation and therapies prior to birth at 23^{+0} weeks.*

   Referral to a tertiary unit can be offered even if comfort/palliative care is the parents' decision. Consideration should be given to the circumstances of presentation, including maternal wellbeing and prognostic factors that help to predict outcome and to ensure counselling and care is individualised and relevant for each family/whānau.

Agreed; the New Zealand College of Midwives believe that the decision to provide active intervention or comfort/palliative care sits with the parents and whanau once appropriate information has been provided to them to assist their decision making.

3. *Antenatal clinical variables that influence the outcome for infants born at periviable gestation include: gestational age in days, fetal growth and wellbeing, gender, preterm prelabour rupture of membranes, evidence of chorioamnionitis, multiple pregnancy, use and timing of antenatal corticosteroids and place of birth (inborn/outborn) (ACOG, 2016)(Express paper 2010 Austeng D et al. (2010), (Raju et al., 2014, Guillen et al., 2012).*

   We acknowledge that some indications for periviable birth relate more specifically to maternal wellbeing (for example, fulminating preeclampsia and medical conditions such as end stage renal disease or severe cardiac disease) and that in these circumstances it may not be appropriate to delay birth to optimise infant outcomes. This should be clearly identified and accounted for in the counselling process.

Agreed; women with significant pre-existing medical conditions will be under the care of the Obstetric team and in some areas also a community LMC midwife. These women should be referred for discussion with paediatric services early in their pregnancy so that they have the optimum time to consider their options if baby has to be born at a periviable gestation.

4. *If presentation is at a primary or secondary unit and active intervention is being considered, transfer to a tertiary unit before birth should be arranged wherever possible. A review of outcomes in New Zealand indicates that if <24^{+0} weeks at presentation to a primary or secondary setting where transfer to a tertiary unit before birth is not possible, infants are unlikely to survive and so comfort/palliative care is more appropriate. (Aotearoa, 2015)*

It is agreed that the optimum management is to transfer women to the tertiary unit to birth wherever possible when they present at periviable gestations, and that survival is unlikely if they present to a primary or secondary unit between 22^{+5} to 23^{+6} weeks gestation. Women should be offered the opportunity to be transferred to a tertiary unit for pre-birth intervention at these gestations if they wish to have active intervention to reduce the chance that they will birth in the secondary unit prior to having the opportunity to be transferred. Currently some tertiary centres do not accept transfers of women before 24 weeks and we understand one centre has stated this cannot change in their district without further resource. Service must be consistent across the country to ensure equity.

5. *In the situation where a woman presents in active labour from 23 weeks at a tertiary centre, or the gestation is unknown with no time to obtain an informed decision with the family, care should be clinically led, with timely review once more information and family views can be obtained.*

Agreed.

6. *Decisions should be reached through a shared decision making approach that is ongoing and responsive to clinical events, especially increasing gestation. Shared decision making implies that parents are at the centre of discussions about the uncertainties in prognosis and what treatment will mean. It should work toward parental preferences informing the decision making with the result that they feel they have a significant degree of ownership over the decisions that are made. It is important to bear in mind that decision making in this area is rarely one decision and is more typically an ongoing discussion and set of decisions for the care of extremely preterm infants.*

While we agree in principle with this statement we are concerned that it leaves room for clinician's bias to influence family's decisions and understand that it is the families who live with the consequences of these decisions, not the clinicians. It has been suggested that unconscious bias influences the number of babies offered active intervention. It is critically important to ensure equity of information provided, access to tertiary level care and of choice to access active intervention (or not) for all parents. Parents must not only feel they have, but actually have ownership over decisions made and parental preferences should always inform decision making and be supported by appropriate information. Below is the statement with our suggested edits.

> Decisions should be reached through a shared decision making approach that is ongoing and responsive to clinical events, especially increasing gestation. Shared decision making implies that parents are at the centre of discussions about the uncertainties in prognosis and what treatment will mean. It should ensure that parental preferences, based on a good understanding of the information shared are paramount in informing the decision making with the result that they have a significant degree of ownership over the decisions that are made. It is important to bear in mind that decision making in this area is rarely one decision and is more typically an ongoing discussion and set of decisions for the care of extremely preterm infants

7. *Standardised written information for the family/whānau should be provided that includes the chances of survival and prediction on later outcomes, including the range and likelihood of disability. It must be acknowledged that there is high variability in the neurodevelopment outcomes for babies born at 23-24 weeks and impairment cannot always be predicted (Raju et al., 2014, Lemyre and Moore, 2017, Guillen et al., 2015) (Younge et al., 2017) (Fellman et al., 2009). The complexity of prognostic information is another reason why shared decision making is important and there is an ongoing communicative relationship with the clinical team and parents. Offering appropriate cultural and spiritual support is recommended to support decision making.*

Agreed; providing the parents' decisions are respected at all times.

8. *Where consensus between parents and health care providers is not reached further opinions should be explored. Facilitated discussion is recommended, possibly with the assistance of someone outside of the clinical team. Options include second opinions from another tertiary centre, a patient advocacy service support, the Bioethics Centre at Otago or a Clinical Ethics Advisory Group*

Assuming families are fully informed of the implications of their decision making, we understand that in the event that parental decision to continue active intervention is at odds with recommendations from clinicians to withdraw care, this may require the suggested process to be undertaken. When it comes to decision making when a baby has no complicating factors aside from the extreme prematurity and parents choose not to access active intervention for their babies and instead choose palliative care, that choice should be theirs to make and should not be challenged. These babies are still at risk of long term neurodevelopmental issues and the parents are making an informed choice.

9. *Best practice management in midwifery, obstetrics and neonatology is constantly evolving and practice guidance should underpin the care provided. Access to checklists, bundle of care, algorithms and parent information will be provided by New Zealand Newborn Clinical Network (Paediatric Society of New Zealand).*

   On approval these will be available via links from a wide variety of national websites accessible to midwives, obstetricians, neonatologists, paediatricians and neonatal nurses. The New Zealand Newborn Clinical Network which will remain responsible for future reviews of these documents.

   This consensus statement will be reviewed in two years from the date ………

The New Zealand College of Midwives supports the ongoing and progressive approach to developing guidance for health professionals and that access to resources will be through the New Zealand Newborn Clinical Network (Paediatric Society of New Zealand) who will also take responsibility for future reviews of these documents. We would expect that review of all documents and guidance would be made in a multidisciplinary team context and that documents would be approved by all provider groups including the College prior to their release.

We also suggest that DHB's have a responsibility to promulgate the final consensus statement throughout their neonatal, obstetric and midwifery teams and that this process should also engage actively with LMC midwife Access Agreement holders. DHBs who have tertiary neonatal services need to engage with the referral centres that are in their geographic catchment to ensure referral and transfer systems and processes support the changes in practice that will result in some areas as a result of this statement.

The College would also like to reiterate their concern regarding the currently insufficient support services for families who have a child with long term neurodevelopment issues in some areas and note that this needs to be addressed. The College could understand the drive to review and lower the viability criteria better, if other systemic changes were being considered along with neonatal intensive care treatment, such as extensive broad support for parents post-NICU to reduce their financial burden, manage their children's complex medical and developmental needs, and address their isolation and mental health challenges.

The College supports a multidisciplinary review of this consensus statement commencing two years from the date it is released.

Yours sincerely

Alison Eddy

Midwifery Advisor

New Zealand College of Midwives